



Colorado Medicaid Benefit Coverage Standard

DISORDERS OF SEX DEVELOPMENT (DSD) OR INTERSEX SURGICAL REMEDIATION

Brief Coverage Statement

Disorders of Sex Development (DSD) refers to a group of genetic, endocrine and physical anomalies characterized by ambiguous external genitalia at birth or by discordance between the external genitalia and chromosomal gender. (Often, the antecedent assessment of chromosomal gender may have been made at the time of prenatal diagnosis.)

Colorado Medicaid covers surgery for treatment of DSD when medically necessary as described in this policy.

PHILOSOPHICAL OVERVIEW OF DSD

Optimal care for children with DSD requires an experienced multidisciplinary team that is generally found in tertiary care centers. Ideally, the team includes appropriate pediatric subspecialists in such areas as endocrinology, surgery, urology, psychology or psychiatry, gynecology, genetics, neonatology, and, if available, social work, nursing, and medical ethics. Core composition will vary according to DSD type. Ongoing communication with the family's primary care physician is essential.

Because the gender effectuated through these surgeries plays such a critical role in a person's life and because surgeries carry the risk of profound effects physically, psychologically and sexually, there has been considerable debate about whether surgical treatment in the first few weeks of life is necessary, when doing so is not critical to the physical well-being of the baby. Colorado Medicaid encourages each family to take the time it needs to make this complex decision.

Since there may need to be further surgery, particularly at the time of puberty, the surgeon has a responsibility to outline for the family the surgical sequence and subsequent consequences from infancy to adulthood.

Services Addressed in Other Benefit Coverage Standards

- None



Colorado Medicaid Benefit Coverage Standard

Eligible Providers

All providers must be enrolled with Colorado Medicaid.

- Only surgeons with expertise in the care of children and specific training and credentialing in the surgery of DSD should perform these procedures.

Eligible Place of Service

1. Office – Testing
2. Clinic – Testing
3. Federally Qualified Health Center – Testing
4. Rural Health Center – Testing
5. Hospital – Surgical Procedures

Eligible Clients

1. All currently enrolled Medicaid clients, aged 20 and younger, are eligible to receive this service.
2. Clients enrolled in the Primary Care Physician Program (PCPP) or Accountable Care Collaborative (ACC) must obtain a referral to a specialist for services to be reimbursed.

Covered Services and Limitations

Intersex surgical remediation is covered as reconstructive surgery if the diagnostic criteria for DSD are met. Procedures can be performed as necessary throughout development, including at the time of development of pronounced secondary sex characteristics during puberty.

Note: Colorado Medicaid supports and encourages that discussions with the family be conducted by a professional with appropriate communication skills and knowledge of DSD. Open communication with clients and families is essential: their participation in decision-making is encouraged and their concerns should be respected. Counseling services related to DSD for the client and family are covered.

Prior Authorization Requirements

All DSD or intersex surgical remediation procedures require prior authorization.

Non-Covered Services

1. DSD or Intersex surgical remediation is **not covered** when the diagnostic criteria for DSD are not met.
 - 1.1. Specifically, trans-sexual surgery (sexual reassignment surgery or SRS) for gender identity disorder alone is not a covered benefit.



Colorado Medicaid Benefit Coverage Standard

2. DSD or intersex surgical remediation procedure is **not covered for adults** aged 21 and older.

References

American Academy of Pediatrics, Council on Children With Disabilities. Care coordination in the medical home: integrating health and related systems of care for children with special health care needs. *Pediatrics*. 2005;116:1238–1244

American Academy of Pediatrics, Section on Urology. Timing of elective surgery on the genitalia of male children with particular reference to the risks, benefits, and psychological effects of surgery and anesthesia. *Pediatrics* 1996;97:590–594

Brown J, Warne G. Practical management of the intersex infant. *J Pediatr Endocrinol Metab*. 2005;18:3–23

Carmichael P, Ransley P. Telling children about a physical intersex condition. *Dialogues Pediatr Urol*. 2002;25:7–8

Cohen-Bendahan CCC, van de Beek C, Berenbaum SA. Pre-natal sex hormone effects on child and adult sex-typed behavior: methods and findings. *Neurosci Biobehav Rev*. 2005; 29:353–384

Consortium on the Management of Disorders of Sex Differentiation. Clinical guidelines for the management of disorders of sex development in childhood. Available at: www.dsdguidelines.org/htdocs/clinical/index.html. Accessed April 23, 2010

Creighton SM. Long-term outcome of feminization surgery: the London experience. *BJU Int*. 2004;93(suppl 3):44–46

Dreger AD, Chase C, Sousa A, Grupposo PA, Frader J. Changing the nomenclature/taxonomy for intersex: a scientific and clinical rationale. *J Pediatr Endocrinol Metab*. 2005;18:729–733

Grumbach MM, Hughes IA, Conte FA. Disorders of sex differentiation. In: Larsen PR, Kronenberg HM, Melmed S, Polonsky KS, eds. *Williams Textbook of Endocrinology*. 11th ed. Heidelberg, Germany: Saunders

Hines M, Ahmed F, Hughes IA. Psychological outcomes and gender-related development in complete androgen insensitivity syndrome. *Arch Sex Behav*. 2003;32:93–101

Lee PA. A perspective on the approach to the intersex child born with genital ambiguity. *J Pediatr Endocrinol Metab*. 2004; 17:133–140

Lee, PA, et. al., in collaboration with the participants in the International Consensus



Colorado Medicaid Benefit Coverage Standard

Conference on Intersex organized by the Lawson Wilkins Pediatric Endocrine Society and the European Society for Paediatric Endocrinology. *Pediatrics* 2006;118/2:e487-e500

Meyer-Bahlburg HF et al. Attitudes of Adult 46, XY intersex persons to clinical management policies. *Urology*. 2004; 171:1615-1619

Meyer-Bahlburg HF. Gender and sexuality in congenital adrenal hyperplasia. *Endocrinol Metab Clin North Am*. 2001;30: 155–171, viii

Money J. *Sex Errors of the Body and Related Syndromes: A Guide to Counseling Children, Adolescents, and Their Families*. 2nd ed. Baltimore, MD: Paul H. Brookes Publishing Co; 1994

Nihoul-Fekete C. The Isabel Forshall Lecture: surgical management of the intersex patient—an overview in 2003. *J Pediatr Surg*. 2004;39:144 –145

Ogilvy-Stuart AL, Brain CE. Early assessment of ambiguous genitalia. *Arch Dis Child*. 2004;89:401– 407

Schober JM. Long-term outcomes of feminizing genitoplasty for intersex. In: *Pediatric Surgery and Urology: Long-term Outcomes*. London, United Kingdom: WB Saunders; In press


Slijper FM Clitoral surgery and sexual outcome in intersex conditions. (editorial) *Lancet*. 2003; 361: 1236-1237

Warne G, Grover S, Hutson J, et al. A long-term outcome study of intersex conditions. *J Pediatr Endocrinol Metab*. 2005;18: 555–567

Wisniewski AB, Migeon CJ, Meyer-Bahlburg HF, et al. Complete androgen insensitivity syndrome: long-term medical, surgical, and psychosexual outcome. *J Clin Endocrinol Metab*. 2000; 85:2664 –2669

Zucker KJ. Intersexuality and gender identity differentiation. *Annu Rev Sex Res*. 1999;10:1– 69



Medicaid Director Signature

Date